DOCUMENT RESUME

ED 456 599 EC 308 584

AUTHOR	O'Brien, Connie Lyle; O'Brien, John
TITLE	The Origins of Person-Centered Planning: A Community of Practice Perspective.
INSTITUTION	Responsive Systems Associates, Lithonia, GA.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Minnesota Univ., Minneapolis. Inst. on Community Integration.; Syracuse Univ., NY. Center on Human Policy.
PUB DATE	2000-00-00
NOTE	29p.
CONTRACT	H133B980047
AVAILABLE FROM	For full text: http://www.soeweb.syr.edu/thechp/wnew.
PUB TYPE	Information Analyses (070)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Adults; *Change Agents; Change Strategies; *Disabilities; Empowerment; History; Independent Living; Individual Power; *Long Range Planning; Normalization (Disabilities); Organizational Change; *Personal Autonomy; Program Development; *Rehabilitation Programs; *Self Determination; Social Change

ABSTRACT

This paper traces the history of person-centered planning in programming for individuals with disabilities. It begins by describing the context shared by the first four methods of person-centered planning to emerge (Personal Futures Planning, Individual Design Sessions, Getting To Know You, and Twenty-Four Hour Planning) and some of their formative influences. The development of the Program Analysis of Service Systems (PASS) and the growth of community service systems sufficiently powerful to support all people, regardless of the severity of disability, is discussed, along with political and parent advocacy influences. It highlights the common agenda of the first approaches to person-centered planning which reflected their originator's involvement in the normalization teaching of community of practice. These approaches included: increasing choice, advocating de-personalizing labels and difference-making procedures, honoring the voices of the person and those who know the person best, building relationships, individualizing supports based on high expectations, and demanding that agencies adopt new forms of services. The paper concludes that person-centered planning has grown because passionate concern to support people with developmental disabilities to discover and contribute their gifts brought people together to form communities of practice. These communities of practice supported the creation of skills and knowledge necessary to organize growing numbers of people and agencies around people's vision of a good life in community. (Contains 57 references.) (CR)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 456 599

THE ORIGINS OF PERSON-CENTERED PLANNING: A COMMUNITY OF PRACTICE PERSPECTIVE

by
Connie Lyle O'Brien and John O'Brien

1999

Responsive Systems Associates
58 Willowick Drive
Lithonia, GA 30038

Preparation of this paper was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B980047) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota, Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily reflect the official position of NIDRR.

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

BEST COPY AVAILABLE

EC 308584

The Origins of Person-Centered Planning

A Community of Practice Perspective

Connie Lyle O'Brien and John O'Brien[1]

Communities of practice 2
A family of approaches 3
New perspectives and possibilities 5
Developments in the normalization teaching community of practice 8
A laboratory 9
A forum 11
A workshop 12
A medium of communication 13
A common agenda 14
Distinctive methods 17
Two approaches with distinct roots 20
Different theories and tools 21
Incorporating lessons from systems planners 22
Continuing development 23
References 24

Thanks to the people who participated in interviews or reviewed this paper: Brian Abery, Marcie Brost, Emilee Curtis, Marsha Forest, Charles Galloway, Susan Burke Harrison, Teri Johnson, Susannah Joyce, Jo Krippenstaple, Sandra Landis, Marijo McBride, Karen Green McGowan, Beth Mount, Jack Pealer, Cindi Pitonyak, David Pitonyak, Michael Smull, Steve Taylor, Alan Tyne, Ann Turnbull, John VanDenBerg, Terri Vandercook, John Winnenberg, and Jack Yates.

[1] Preparation of this chapter was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B980047) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

© 2000 Responsive Systems Associates, Inc.
All rights reserved.

Like other efforts for social change, person-centered planning has been used and misused, complicated and simplified, lengthened and shortened, trivialized, legalized and lionized. As an aid to those who use person-centered planning to improve life conditions for people with disabilities, this chapter offers one account of how the family of approaches to person-centered planning developed. We describe the context shared by the first four methods to emerge (Personal Futures Planning, Individual Design Sessions, Getting to Know You, and Twenty-four Hour Planning) and indicate some of their formative influences.

This is recent history as viewed by insiders. We understand person-centered planning as a systematic way to generate an actionable understanding of a person with a developmental disability as a contributing community member, and we can identify eleven distinct and mostly related approaches that developed during what we think of as its formative period: 1979 to 1992. To prepare we interviewed some of the originators of each approach and collected and read training materials, reports, manuals and accounts of person-centered planning published before 1992.[2]

Because we are remembering our own thoughts and activities as well as interviewing friends and reading familiar documents, we can make no claim to distance, much less any approximation of objectivity. Our engagement may have amplified some influences at the expense of others or blinded us to distinct approaches to person-centered planning that developed outside our own network. Such omissions arise from ignorance (or maybe from defining what could be considered a distinct approach as a variation of one of those we identify), not from any claim to act as the arbiter of what is or is not person-centered planning. These omissions are more likely in the time between 1985 and 1992 as the ideas and tools of person-centered planning were more and more widely disseminated.

Communities of practice

It is reasonable to look at person-centered planning as a collection of techniques each of which has particular defining features and a distinct history associated with particular leaders. However, we have chosen another way to organize this discussion. We want to explore the emergence of person-centered planning from the point of view of communities of practice, a way of understanding how knowledge and skill are created and shared that puts learning in the context of social engagement (Wenger, 1998). Communities of practice are *"groups of people informally bound together by shared expertise and a passion for a joint enterprise"* (Wenger and Snyder, 2000, p. 139). People select themselves into communities of practice because of personal interest in building and exchanging knowledge with others who share their commitment to an issue or a task. Communities of practice develop knowledge and invent necessary skills by allowing people to build up and act in terms of a shared context: a set of common meanings and stories that allow them to understand a social world that matters to them and take effective action to change it.

[2] References identify published versions of materials that usually circulated for some time before finding their way into print, so dates in the bibliography are not a reliable guide to when things were first written and used. Most materials passed from copy-machine to copy-machine and can be hard to locate. We have tried to partially remedy this in O'Brien & Lyle O'Brien (1998).

We have an agenda to promote by adopting this point of view. We notice that agencies that want to benefit from person-centered planning often act as if person-centered planning were a sort of tool box of techniques which staff could be trained to use in workshops by studying protocols, hearing about ideas, and perhaps trying out a technique or even two for homework. Such context-free training no doubt teaches something, but we think it deprives learners of the kinds of social supports for inventive action that were available to the people who developed the first approaches to person-centered planning. This seems to us like a prescription for a system fix destined to fail in its purpose of promoting better lives by disclosing people's capacities and gifts.

The community of practice that shaped all of the earliest approaches to person-centered planning functioned between 1973 and about 1986 among people from across North America who shared a passion for understanding and teaching how the principle of normalization might be applied to improve the quality of services to people with developmental disabilities. As the work spread to Britain in 1979, this community of practice became transatlantic, generating cross-national exchanges that extended available perspectives and skills and offered a ready channel for sharing and refining approaches. (For a very helpful account of person-centered planning in Britain, see Sanderson, Kennedy, and Ritchie, 1997). This community of practice provided the originators of person-centered planning with a laboratory for closely observing how services affect people's lives, a forum for discussing the difficult questions that arise in the work of providing services and formulating ideas grounded in their experience, a workshop for inventing new ways to explore the experience of people with developmental disabilities, and a medium for communicating new ideas and techniques.

In describing the community of practice from which these first approaches emerged we are not yearning for the good old days. We do think it wise for those who want proficient person-centered planning to invest in the kind of long-term, regular, face-to-face sharing of activities, stories, and questions that will build communities of practice able to create knowledge and skills relevant to today's opportunities and challenges. We also hope that describing some of the beliefs and assumptions that shaped the emergence of person-centered planning will help those who were not then involved to make sense of what has developed.

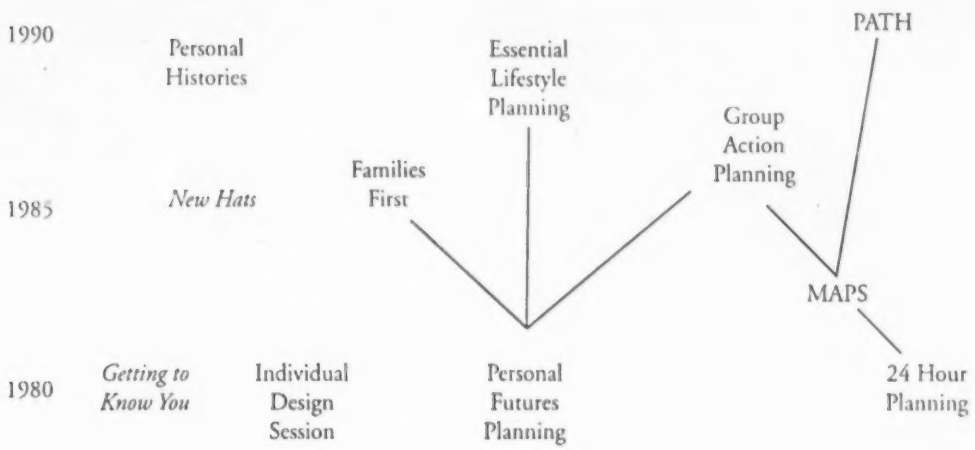
A family of approaches

In 1979, Karen Green-McGowan and Mary Kovaks began a series of workshops on 24-hour planning for people with severe disabilities sponsored by the Canadian National Institute on Mental Retardation. By 1980, Beth Mount was training her Georgia colleagues in Personal Futures Planning, Jack Yates was leading people in Southeastern Massachusetts in Program Design Sessions for people moving out of Dever State School, and Marcie Brost, Terri Johnson and their co-workers were planning with people from three county service boards as a way to define the capacities Wisconsin's system would need to develop in order to deliver individual-

ized services. As we will see, these distinct efforts grew from common roots in a network of normalization teachers and their originators. It is the genesis of these four initial efforts that will primarily concern us in this chapter.

By about 1988, person-centered planning had grown well beyond the immediate reach of the people who developed the first dozen approaches. More and more people were moving the techniques they learned in workshops or by reading into new settings for new purposes. A few regional and state administrators were considering the question of how to make person-centered planning routinely available on a large scale. Over the four following years, interest continued to grow. In June 1992, the Pennsylvania Office of Mental Retardation sponsored a conference that gathered people involved in various approaches to person-centered planning to inform the implementation of the state's strategic plan (O'Brien and Lovett, 1992). We have chosen this event, with its debate about the costs and safeguards for mandating person-centered planning as a matter of state policy, to mark the close of its formative period.

This family tree identifies eleven early approaches to person centered planning that developed between 1979–1992 and suggests generational influences among them. (Brief references to approaches other than the first four will be found in the last section.)



Since 1992, many more variations have developed as a growing number of practitioners and agencies have adapted these approaches to new circumstances and developed their own methods. Today, some approaches, like Essential Lifestyle Planning, are widely practiced and continuing to spread; others, like Individual Design Sessions, continue to develop in the niche where they were born; still others, like *Getting to Know You*, have nearly dropped from use.

The heading *person-centered planning* became common by 1985. It expresses the family resemblance among these different methods and suggests that they share common genes. This heritage was said to include: seeing people first rather

than relating to diagnostic labels; using ordinary language and images rather than professional jargon; actively searching for a person's gifts and capacities in the context of community life; and strengthening the voice of the person and those who know the person best in accounting for their history, evaluating their present conditions in terms of valued experiences, and defining desirable changes in their lives (Mount, 1992).

Person-centered planning did not emerge full blown. Scores of people worked out its methods in their common attempt to support people with disabilities to compose their lives. People did not begin to purposely apply these approaches to individual planning until about 1979, but the four at the base of the family tree have common roots in the community of practice that promoted the adoption of the principle of normalization between 1973–1986.[3]

Understanding the origins of person-centered planning requires both a broad sense of trends shaping disability services and a more particular sense of the evolution of understanding and practice among the people interested in teaching and applying the principle of normalization in the development of community services.

New perspectives and possibilities

After taking a course in recent American history, one of our nephews observed, "A lot of the '60s happened in the '70s." For social change minded people with disabilities and their allies the 1970s crackled with hopeful activism. Many drew strength and strategies from the struggle for civil rights, the struggle for women's rights, and the struggle against the Viet Nam war. In this brief review of a decade, we focus on events and ideas which engaged and influenced many members of the community of practice that created the first approaches to person-centered planning.

In *The Origin and Nature of Our Institutional Models,* Wolf Wolfensberger (1969) used an intellectual history of mental retardation services to vividly sketch the powerful and mutually reinforcing connection between how society sees people with disabilities, the shape of the services professionals consequently offer, and the impact of these services on the lives of people who rely on services. He illuminated the practical differences it makes to understand people with disabilities as citizens and developing persons rather than as sub-human, as menaces, as objects of ridicule, as sick, as burdens of charity, as eternal children, or as holy innocents. This perspective offers a powerful tool for deconstructing common service practices and points a way to improve life conditions by emphasizing personhood, citizenship, and developmental potential. This analysis appeared alongside the first written expression of the principle of normalization (Nirje, 1969) in a volume commissioned by the recently formed President's Committee on Mental Retardation to explore changing patterns in services. This influential volume was followed by the publication of Wolfensberger's more theoretically rigorous definition of the principle of normalization (1972), a definition operationalized in *Program Analysis of Service Systems* (PASS) (Wolfensberger and Glenn, 1972 and 1975).

[3]The first intensive, practicum-based training in the application of the principle of normalization through PASS (Program Analysis of Service Systems) (Wolfensberger and Glenn, 1972) was held in 1973. By 1986, the network of people working to promote the principle of normalization had divided on questions of the proper role of human services in society and in people's lives, the significance of innovations like supported employment and supported living for the future role of congregate services, the aims and methods of teaching, and Wolfensberger's re-conceptualization of the principle of normalization as social role valorization. After 1986, an international group of teachers affiliated with Wolfensberger continue to provide intensive training in social role valorization, but most of those involved with person-centered planning have moved into other ways of learning and teaching for social change.

The growth of community service systems sufficiently powerful to support all people, regardless of the severity of disability – in Nebraska's regional system, in Macomb-Oakland Regional Center in Michigan, and in Eleanor Roosevelt Developmental Services in New York's Capital District– laid a practical foundation for action on the increasingly incisive criticism of institutionalization emerging from Syracuse University's Center on Human Policy (e.g. Blatt, 1973; Bogdan, Taylor, deGrandpre, and Haynes, 1974, Biklen, 1977).

The National Institute on Mental Retardation (NIMR), sponsored by the Canadian Association for the Mentally Retarded (CAMR), built a national initiative around these US regional service achievements, aiming to demonstrate regional comprehensive community services systems that would make institutions unnecessary. This initiative, called COMSERVE, gave Wolf Wolfensberger a base to refine, teach, and publish his ideas about planning and implementing comprehensive services, evaluating service quality, renewing voluntary organizations, and creating citizen advocacy programs. COMSERVE also supported the first series of training and consultation events that drew together a community of practice around normalization teaching. When Wolfensberger founded his Training Institute at Syracuse University, these efforts began to include and influence more people in the US.

Legal work aimed at social change for people with mental retardation excluded from school or trapped in institutions developed rapidly (Kindred, Cohen, Penrod, & Shafer, 1976). Exposes and landmark legal cases further discredited institutionalization, reinforced an understanding of people with disabilities as a disadvantaged and segregated minority, and fueled the move to develop comprehensive services in local communities. The fact that many professionals continued to defend institutions and advocate for congregate services and segregated special education opened deep questions about the legitimacy of the professional perspective. Much service activity seemed to fall under the shadow of handicapism (Biklen and Bogdan, 1976). As Burton Blatt (1981) pointed out, it is possible for well meaning professionals to destroy lives by telling stories.

Physically disabled activists incorporated the Berkeley Center for Independent Living in 1972, organized to override the veto of the 1973 Rehabilitation Act with its application of civil rights language in section 504 to forbid discrimination on the basis of disability, and committed civil disobedience to force the Secretary of Health, Education, and Welfare to sign implementing regulations. Near the end of the decade, this spirit touched survivors of mental retardation institutions, who organized to proclaim that they are People First, to attack the process of labeling that justifies their exclusion from the opportunities of everyday life, and to make their voices heard in the governance of services.

Powerful ideas about the practical contrasts between typical and valuing ways of understanding disabilities grew out of the lived experience of disabled activists. These ideas crystallized in a number of versions of these two paradigms. (From normalization teaching materials developed in 1979 based on DeJong (1979).)

	Rehabilitation View	Independent Living View
Terms for defining the problem	Impairment/skill deficiency	Dependence on professionals, relatives and others who take over control of your life.
Where is the problem located?	In the person	In the environment & the way services do their work
What's the solution?	Professional intervention	Removal of barriers, advocacy, consumer control, & self-advocacy
Who is the person?	Patient/client	Person/citizen
Who's in charge?	Professional	Citizen
What defines results?	Maximum possible individual functioning as judged by professionals	Living independently (being in control of your life regardless of how much assistance you need to do so)

Political action and litigation by parent advocacy groups resulted in growing state investments in community services as well as in state and then federal legislation establishing a right to education for children of school age. Legislative requirements of individual planning as a foundation for special education, rehabilitation, community services, and institutional services provided opportunities to discover both the power of the multidisciplinary professional voice and the service system's very limited capacity to differentiate and respond to individuals that was covered up by the welter of activities surrounding the writing of "I (fill in the blank with the appropriate letter) P's" (Weatherly, 1979).

The work of researcher-practitioners like Marc Gold (1972), Lou Brown (1976), and Tom Bellamy (1979) and their colleagues and students clearly demonstrated that people with severe disabilities were habitually, reflexively, and profoundly underestimated by almost all of the professionals who assessed their capacity to learn and to work. As the American Association for the Education of the Severely and Profoundly Handicapped (AAESPH, later TASH), formed in 1974, set-up conferences and a journal to broadcast their findings, more and more people built on them. The contrast grew between people's potential with good assistance and the lives that too many people were forced to live by professionals who would rather attribute incompetence to people with disabilities than face what they themselves did not know how to do.

The engagement of sociologists who brought qualitative methodology and a phenomenological perspective to understanding the daily lives and social possibilities of people with developmental disabilities had a powerful effect on the development of person-centered planning (Bogdan and Taylor, 1975; Taylor and Bogdan, 1977). Framing developmental disability as a social construct opened new space for seeking to understand the experience of labeled people from their own perspective.

Developments in the normalization teaching community of practice

From 1973 to around 1986, the normalization teaching community of practice provided the people who originated the first approaches to person centered planning with a laboratory, a forum, a workshop, and a medium for communication. Each of these functions played a direct role in shaping the early years of person-centered planning.

This community of practice grew up among people who found PASS a powerful way to understand the relationship between disability, service policy and practice, and community life. Though designed primarily as an instrument for quantitative program evaluation across all of the human services (and still presented in that way by Wolfensberger and his associates, see Flynn, 1999) and secondarily as a way to teach the normalization principle, many teachers found most benefit in PASS as a way of learning about the relationship between people with disabilities and service programs from the perspective of normalization.

PASS workshops were intensive, taking five demanding days and typically involving between 60 and 70 participants who worked as a large group to learn the conceptual foundation and in teams of 10-12 to practice the process of looking at services from the perspective of the principle of normalization. Team practice, guided by an experienced team leader and usually an assistant team leader, included at least one practicum visit to assess a service program. Practica included observation and extensive discussion of program quality from the perspective of the 34 dimensions of the normalization principle defined by PASS and 16 dimensions of program quality relating to administrative effectiveness.

For many reasons, PASS did not catch on widely as an official evaluation tool, and, except in a few regions, PASS training was not particularly well or systematically funded (see Thomas, 1999). A workshop required a number of teachers, typically 10 to 14. By the late 70's there were as many as 40 workshops a year in North America and Britain and some workshop sponsors made a practice of inviting some teachers from other places to join in building up their local cadre of teachers. The hard work of offering training on a controversial way to understand services built many strong relationships.

Only a very few people tried to make a living doing normalization training, so most teachers had other work, usually in the human service professions or in human service administration. A number of parents of people with developmental disabilities and a few people with disabilities participated in the workshops but only a few who were not also employed in the field became teachers. Most workshops were substantially subsidized by teachers' regular employers allowing them released time and more than a few teachers used their own vacation time to contribute to the work.

In addition to basic workshops there were occasional advanced workshops and a number of consultation assessments which invited experienced PASS practitioners to assist a program, typically a program led by another member of the network.

A laboratory

The various activities created by members of the normalization teaching community of practice provided a laboratory for the close observation of how service programs functioned. While practitioners of either qualitative or quantitative research could find much to criticize in the process, PASS encouraged looking carefully at a program from the point of view of the people the program serves. Observation, and the following evaluative discussion, focused on a set of questions and criteria derived from the principle of normalization, and the practice of seeking consensus among team members on conclusions about each dimension of service quality stimulated extensive discussion of the sort that often surfaced different understandings, values, and mindsets among team members. Feelings often ran high in these discussions as participants struggled to digest the implications of what they had observed. Writing reports on consultation assessments demanded deeper thinking and offered a vehicle for disseminating ideas.

Members of the community of practice had repeated chances to look at the same world that they functioned in everyday, but from the position of outsiders charged to identify and think about what the people served experienced through the program. A discipline of accounting for what teams observed rather than explaining why service programs were constrained from doing better built awareness of the potential damage human services can unknowingly inflict. Many participants changed their own practice based on what they learned by assessing another program.

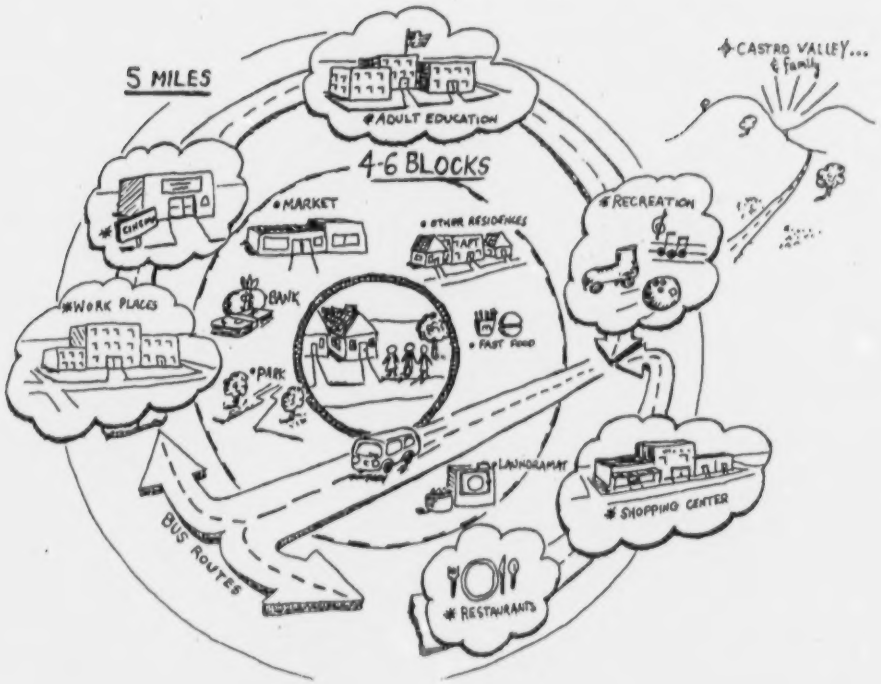
Through the lenses provided by PASS, the originators of person-centered planning learned difficult lessons. They learned that opportunities for improvement which are evident to people with disabilities and those who care about them as people are very often obscured, ignored, or dismissed by powerful people in their lives as "impossible" or "unrealistic" based solely on the untested assumptions of the powerful person. They learned how difficult it is to consistently and intensively provide people assistance that is truly relevant to their development. Even those individual plans that specified relevant assistance typically did not predict what people did day-to-day with the staff available to them. They learned that people's social worlds were typically very constricted, even when they were served in ordinary looking buildings on ordinary local streets. They learned that alternatives to controlling and disciplining people with disabilities in groups of stigmatized people were rare and themselves raised significant dilemmas. They learned to expect a disconnection between a program's stated aims and its daily activities and they found that only a rare few service organizations had any way at all to discuss and work toward closing this gap. They learned that meeting ordinary needs for the security of a comfortable home, and people to love and

care for, and good work to do is typically beyond the reach of a human service that is not consciously and systematically committed to developing its own organizational capacity.

There was good news as well as hard lessons. Many network members avidly collected examples of good practice. Stories and data about people with disabilities pioneering employment, supported living, and membership in community networks and associations traveled quickly and widely to an audience sensitized to appreciate their importance.

A few projects were funded to apply what community of practice members had learned in new contexts. Two, which were widely discussed among the network, focused on linking individual plans to individualized budgets. One project assessed the capacity of three Wisconsin county service boards based on plans and individual budgets developed with 92 people and their families. This study pursued a two part question: *"What specific goods, services, and other supports does each individual need to be a respected, participating member of his/her community and what needs to happen for these services and other supports to be made available by the right people in the right place at the right time?"* (Brost & Hallgren-Ferris, 1981 p. 1).

The second project focused on a single individual, responding to a judge's order to develop effective community supports for an institutionalized young woman (Galloway, 1981). In it's framing of Sharron T's move from the institution as a "passage to community participation", this detailed plan made imaginative use of the PASS teaching notion of designing services based on "culturally valued analogues". This means asking, *"What does this service compare to in the world of valued citizens and what would it take to offer the same variety of opportunities to people who rely on services?"* As the graphic below indicates, pursuing this question and viewing the work as assisting someone to journey safely from surviving in the culture of an institution to moving competently in the unfamiliar culture of community defined a far different setting for Sharron and her two "Teaching Companions" than the specialized group home design anticipated by the service system.



The people who gave shape to the first approaches to person-centered planning knew from their time in this laboratory that mission statements, and regulations, and inspections, and policies, and individual plans on paper are useless unless people act on a commitment to each other. They knew the hellish difficulty of overcoming isolation from community life and escaping reproduction of the web of control that surrounds most people with developmental disabilities. They knew that with disciplined effort and careful listening it is possible to learn a little bit about a person's perspective on their life and what they think would improve it. They knew from experience that attending closely and openly and thoughtfully to a person with a disability –even for a little while– could draw one into caring about how that person's life goes on.

A forum

Every careful look at a service program raised more and deeper questions about the relationship between disability, organized services, and community. Looking closely and thinking carefully about brief snapshots of people's experience troubled the understanding of each term.

For example, the struggle to realize the value of social integration, understood as the active opportunity to grow in a variety of good relationships with others, including people without disabilities, made the shared understanding of community deeply problematic. Members of the community of practice knew that such relationships were possible. Indeed, all of the originators of the various approaches to person-centered planning had (and have) such relationships themselves. But

BEST COPY AVAILABLE

services very seldom do well in facilitating such relationships outside their own boundaries.

In the forum created by ongoing teaching, members explored both the meaning of social integration and some of the means to build good relationships. This made news from citizen advocacy initiatives (local organizations that match and support people in a variety of one-to-one relationships) and the growing number of circles of support relevant, especially in the development of Personal Futures Planning (Mount, 1984; Mount, Beeman, and Ducharme, 1988).

The continuing forum for refining and developing new ways to understand and explain the relationship between disability, community, and organized services led some to explore alternative ways of framing the search for service quality. The most elaborated such understanding found expression at about the same time that the first approaches to person-centered planning emerged. Interest in the work of Thomas Gilbert (1978) led Charles Galloway and John O'Brien to re-think service effectiveness in terms of accomplishments (Galloway, 1978, O'Brien, Poole, and Galloway, 1981). The idea of accomplishments provided part of the conceptual structure for *Getting to Know You*, Personal Futures Planning, and 24-Hour Planning, though the number and labels for the accomplishments bounced around for a time before settling at five dimensions of experience in which service practice can make a significant difference to the lives of people with disabilities: community presence, choice, respect, competence, and community participation (O'Brien, 1987).

A workshop

Members of the network of normalization teachers regularly faced groups of people with different outlooks, different values, and different styles of learning. Normalization teaching provided a workshop for inventing and testing new ways to facilitate learning about the effects of services on the quality of people's daily experience and their connections to community life. Three innovations in the process of normalization teaching were of particular importance in the development of person-centered planning.

As experience grew, it became clear that PASS teams benefited from spending time in thoughtful discussion of the overall situation of the people who rely on the service whose quality the team is assessing before jumping in to a discussion of service particulars. Two simple questions guided these discussions, which often moved the group to surface and work through significant differences among themselves. These questions are, *"Who are the people served?"* and *"What are their most important human needs?"* These discussions proved most fruitful when people used ordinary language to describe people's needs and the consequences of their impairments rather than taking refuge in professional jargon.

By adding only one question to these two, *"What would have to happen to meet these needs?"*, Jack Yates developed a format for engaging staff in reviewing

their own program, which he called Program Design Sessions. When Bertha Young, the director of a community service agency and an active member of the normalization teaching community of practice, asked Jack Yates, "Why not work through these questions around one person instead of a group of people?", the format for Individual Service Design emerged. Exactly because these questions are so simple, facilitating a discussion that moves below superficial comments and cliched understanding requires great mastery on the part of the group leader. Repeated practice in teaching PASS helped a number of community of practice members develop such mastery, though such experience was not the only source of the necessary skill, as Herb Lovett's long and creative use of Individual Service Design demonstrated.

Over time, the power in striving to look at a service program from the point of view of the people who rely on the program led a number of teachers to shift the service assessment's perspective. Teachers learned simple, effective ways to pair team members with particular people a program served in order to encourage them to view the program from that person's place within it. For example, team members might look very closely at what happens for a person who needs assistance eating during a meal or during a time scheduled for training. As team members considered their observations, they asked *"What are the likely consequences for the people we met if current practice does not change?"* (Note that the focus is on noticing what happens; team members are not asked to pretend to understand the other person's inner experience.)[4] This provided the originators of person-centered planning with a good deal of practice in facilitating groups thinking from a person's point of view. Twenty-four-hour planning makes explicit use of this kind of predictive question, asking, *"What is this person at greatest risk for, if we do not change his or her life?"* (Green-McGowan and Kovaks, 1984).

Graphic facilitation (Sibbet, 1977) introduced a way of guiding discussion and information gathering by combining words and simple graphics. It also stimulated the creation of graphic templates and tasks to structure the collection and display of information. Photocopies of a growing number of these templates and tasks passed from hand to hand for several years until they were collected in a handbook (O'Brien, 1981). Some level of graphic facilitation found application in 24-hour planning and Individual Service Design and it became a hallmark of Personal Futures Planning.

A medium of communication

Year on year the community of practice grew, engaging most of the originators of person-centered planning with one another and with a growing number of people who shared the demanding and exciting experience of teaching people about normalization through PASS. As person-centered planning took shape, some of the members of this growing network would become early adopters of an approach, others would collaborate in developing the approach, others would

[4] Wolfensberger (1983) strongly disagreed with this move from looking at a program as a whole to looking at a program from the point of view of a few of its participants. He believes that such practices compromise the use of PASS (or its cousin PASSING) as objective instruments for service evaluation.

sponsor projects that refined and extended the reach of the approach, still others would become its critics.

People in the community of practice spoke a common language and could count on each other to have some skill in facilitating and usefully recording discussions about the tough questions and interesting possibilities at the intersection of people's lives and the daily reality of services. When Jack Yates (1980) wrote about his preferred format for a meeting's "wallpaper", he knew that his readers would be thinking about writing on big sheets of paper taped to the wall and when he referred to "age-appropriateness" he could be confident that most of his readers would grasp the nuances of the issue and not misunderstand it superficially as a crusade to tear beloved stuffed animals from the arms of adults with developmental disabilities.

This common language and skill set made it reasonably easy for people across the community of practice to try out different person-centered planning approaches and to provide originators with fast feedback on results and news about variations they invented to deal with particular problems arising in practice.

A common agenda

The first approaches to person-centered planning shared a common agenda which reflected their originator's involvement in the normalization teaching community of practice. The themes of increasing choice, avoiding de-personalizing labels and difference-making procedures, honoring the voices of the person and those who know the person best, building relationships, individualizing supports based on high expectations for the person's development, and demanding that agencies adopt new forms of service and organization to provide newly conceived supports express an agenda that each approach to person-centered planning followed in its own distinct way. A typical way to communicate what person-centered planning was all about was to draw a strong contrast between usual practice and belief and person-centered practices and beliefs, as illustrated by the two tables below, quoted from documents widely circulated in early training.

Perhaps the most powerful idea underlying person-centered planning is that the way a person who needs services is seen and understood by those who deliver that service generates a powerful internal consistency in the ways the person is served. Trying to make changes in procedures or settings offers far less leverage for changing services than shifting the understanding of a person. This table (Mount, 1984) expresses a contrast that deconstructs the logic of the activity center that currently serves George and outlines a common sense response to him as a person which is masked by the internal consistency of George's current program.

Congregate Service Perspective		Connections Perspective	
Who is George?	**What does he need?**	**Who is George?**	**What does he need**
• A person with a mental age of 4 years 3 months	• A program for children	• A 40 year old man who has missed most typical experiences and has never had a real job	• A lot of experiences
• A person with IQ >30	• To be protected from the world	• A person with no income who is poor	• A real job
• A person who is severely mentally retarded	• To learn very simple tasks	• A person who has been isolated all his life	• An income
• A person who has "an indication of organicity, including difficulty with angles, closure, retrogression, over-simplification and an inability to improve poorly executed drawings."	• To learn these skills separately from non-disabled people because he is so different from them	• A person who has no contacts or connections to the wider community	• To be included and present in the community
• A person with acute temper flare-ups directed at staff	• Highly specialized staff who can address issues of retrogression, closure, etc.	• A person who has little control over the direction of his life	• Relationships to other people, connections to community
	• An environment where his temper can be controlled	• A person who has more difficulty learning new skills than most people	• Friends
	• To be repaired and sent back to the real world when he is better controlled	• A person who is treated as a child by his mother	• Vision for the future and support in getting there
		• A delightful man who makes a difference in the lives of those who care about him	• Someone who can speak out on his behalf
			• A lot of support for learning
			• More people who see and treat him as an adult
			• People who can enjoy him
			• More people who see and treat him as an adult
			• People who can enjoy him

The person-centered planning process makes three important moves. One, it re-frames differences in performance that justify diagnostic labels in terms of differences in life experience. George acts age-inappropriately, in part, because those close to him treat him as a child. He needs more people in his life who see and treat him as an adult and facilitate his participation in the adult world of work and community. Two, it directs attention outside the orbit of service programs. George is poor and has missed many typical experiences. He needs a real job of the sort only available in the real world and not at his group's table in the activity center. Three, it brings George's capacities to the foreground. George is a delightful man to those who know him. He needs more people to enjoy him. Those who think inside the logic of congregate services will experience dissonance if they make these three moves. This dissonance can motivate change but, paradoxically, it can also stimulate a re-commitment to the familiar logic of congregation. To support their retreat, people re-cast person-centered planning

in terms that make it consistent with service-as-usual. Managing this paradox in ways that preserve person centered planning's leverage for system change continues to trouble its originators (Lyle O'Brien, O'Brien, and Mount, 1997).

Typical individual planning happens inside the logic of the sponsoring service program. The way individual planning is done reflects and reinforces the assumptions underlying the program. Person-centered planning confronts these assumptions explicitly and seeks to build its practice on a different logic. This table, taken from the manual for *Getting to Know You* (Brost and Johnson, 1982, pp. 6-7), expresses a criticism of usual individual planning approaches in terms familiar to members of the normalization training community of practice.

Our Assumptions	Perspectives on Traditional Approaches
1. All people, with and without disabilities, share the same basic needs. As human beings, all of us are concerned about having experiences throughout our lives that provide us with: a) autonomy and independence, b) individuality, c) love and acceptance through presence and participation within a family and community, d) stability and continuity, e) continuous growth and learning, f) community status, g) security with respect to personal finances as well as protection of our legal and human rights. People who have disabilities do not have qualitatively different kinds of needs.	1. "Even though you say you value me as a person, my experiences tell me that you are unable to distinguish me from my disability. Your assumption seems to be that people with disabilities are more different than like you who are non-disabled. Your society operates as if my disability and the problems it presents are the most important, and perhaps the only thing worth mentioning about me. From here it is a short step to you seeing me as "a problem."
2. Description of disability is relevant only to the extent that the disabling condition complicates the fulfillment of the above-mentioned needs. What people who are disabled do not have in common with non-disabled people is the independent ability and means to create conditions, situations, and experiences in their lives to meet some or all of their basic human needs.	2. "Once I, as a person with a disability, am seen as 'a problem', it becomes increasingly difficult for you to view me as a real human being. The question of 'What do I as a person need?' becomes 'How do you deal with me, this problem?' Too often, your thinking begins to follow this logic: • "This person is disabled!" • "His/her disability is a problem!" • "This problem needs to be fixed!" • "Special people are needed to fix it!" • "It can only be fixed in special places!" • " It needs to go to one of those special places to be fixed!" • "It can only come back, or come out, when "it" is fixed!" This scenario is one of the most real and most overwhelming barriers that stand between me and the rest of the world.

3. Because disabilities complicate people's lives in ways that ultimately make it more difficult for them to meet their own needs independently, some form of help is required. "Help" can be provided in a variety of ways, in many places, by many people. The form of help and the ways in which it is designed and arranged determine whether or not people get their basic human needs met. It is common to hear phrases such as "Joe Smith needs speech therapy." A more accurate wording would be: "Joe Smith, like all of us, needs to be able to communicate effectively in order to express his needs and preferences and to socialize. His disability interferes with communication ability in several specific ways. Speech therapy is *one* form of organized paid-for assistance that *might* help him meet his communication needs."	3. "Your line of thinking prevents you from asking the right questions about me and other people with disabilities and our needs. The questions that you ask focus on what is wrong with me and are designed to determine my levels of functioning and the degrees of severity of my disability. The results are usually a short perfunctory list of my 'strengths' well as lists of services that need to be purchased in order to 'fix' me." "When I as a person with a disability become a disability and then become the problem, my needs are only seen as services. When my needs become defined as service types, professionals, and places (e.g., 'he needs physical therapy, a behavior management expert, a group home'), it is easy to lose sight of my more basic human needs that your services were meant to address in the first place.
4. The goal of the human services system should be to join forces with natural unpaid support networks (families, friends, neighbors, co-workers, citizen advocates, etc.) to create conditions and support for people with disabilities to live within their local communities. Services should be designed and delivered to enhance each person's capacity for growth and to convey the conviction that each person can participate in some valued role in the community. This goal is valid regardless of a) the type of disability or problems presented, b) the extent to which the disability complicates service provision, c) current lack of services required by the person, d) scores achieved on tests or scales, e) past involvement with the service system. If we view people with disabilities as individuals first and the difficulties they encounter as a result of disability as secondary issues, our vision of their needs will focus on ordinary human needs and the multitude of forms of assistance possible to help meet those needs.	4. "Too often your services are designed and arranged in ways that ignore my current and potential natural, unpaid supports and in ways that restrict my growth, maintain my dependency, and deny me opportunities for community presence and participation" "Assessment becomes a way to rationalize excluding me on the basis of type or extent of my disability, test scores, past experiences, or lack of appropriate services." "If you view me and other people with disabilities as disabled first, then your vision of our needs will focus on fixing or alleviating our problems through paid services, and you will overlook opportunities to involve our families, friends, neighbors and co-workers."

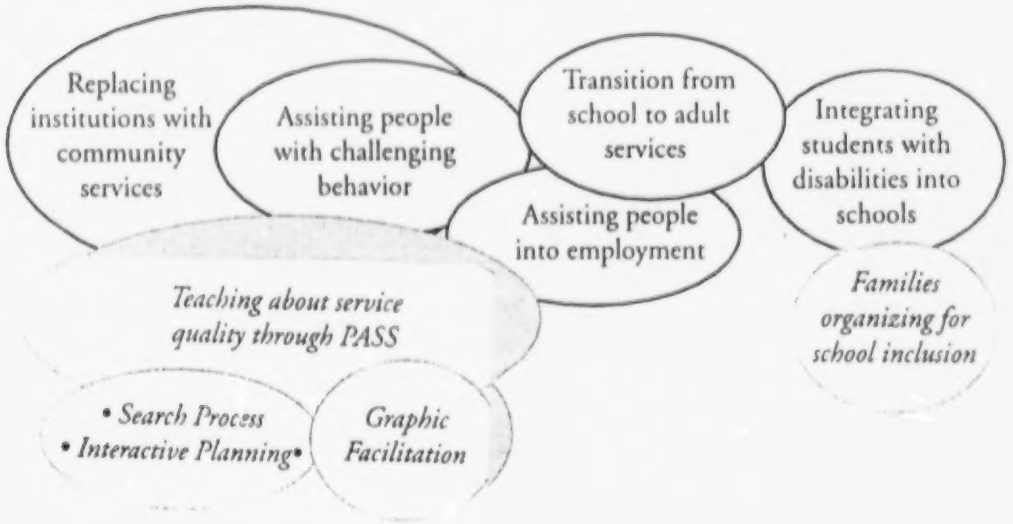
Distinctive methods

Because people can belong to and be influenced by more than one community of practice at a time, and because over time people can move from one community of practice to another, the idea can help explain how approaches with common roots and common agendas differentiated from each other. Differences grew because practitioners engaged distinct issues and settings, drew on different theories and tools to shape their processes, and formed new communities of practice around each approach.

Different issues

As the diagram below suggests, person-centered planning developed in the context of an overlapping set of communities of practice that grew up around

some of the issues that shaped the field of service to people with developmental disabilities from 1975 to 1985. These were concerned with directly improving life for people with developmental disabilities in school, in the transition to adult life, in employment, in the move from institution to community, especially when difficult behavior or severe disability threatened to leave people no alternative to institutionalization.


Replacing institutions with community services
Assisting people with challenging behavior
Transition from school to adult services
Integrating students with disabilities into schools
Assisting people into employment
Teaching about service quality through PASS
Families organizing for school inclusion
• Search Process
• Interactive Planning•
Graphic Facilitation

Twenty-four-hour planning grew from a concern for people whose chances for effective community services were significantly reduced by the complexity of their disabilities. Drawing on their own successful work in creating effective services for people with profound, multiple disabilities, Karen Green and Mary Kovaks developed training and consultation that focused service development on careful individual plans that specified the exact settings and supports a person would need in order to engage in functional and meaningful activity. Here is an example from a plan developed with a 20 year old man identified as "the most medically fragile" person in a 1,200 person institution and his family. Given the perception of Jerry as embodying a devastating disability and the resulting institutional service arrangements that the system assumed were essential to his survival, a plan that called for Jerry to live in his own place with non-disabled peers and make choices among community activities profoundly challenged the imagination and skill of those responsible for Jerry's services (Green-McGowan and Kovaks, 1984, p. 9-10). In their formulation, these goals presume that the institution cannot offer Jerry what he needs to grow and develop. As might be imagined, this made the plan the locus of controversy between advocates for institutional improvement and advocates for institution closure; a controversy in which Jerry's advocates prevailed.

BEST COPY AVAILABLE

1. Jerry's goal for community presence

From: *living in a ward with 60 persons labeled "medically fragile" in an institution of 1200; being worked with by nurses and aides who bathe, feed, dress, change and give medication; getting one hour of "music therapy" a week, staying in bed when he had seizures*

To: *living in the home with at least one non-handicapped age peer and no others with handicaps; being worked with by his peer on experiencing five other environments per week (i.e., leisure time, basic necessity, watching/helping with real work); being allowed individualized recovery time after seizures.*

2. Jerry's goal for rights and personal interests

From: *crying, grabbing, grunting, eye pointing and withdrawing; having no consequences for decisions*

To: *head signals for yes or no; eye or finger pointing to eight to ten symbols representing persons, objects, places; making two to five choices for breakfast, lunch and dinner; choosing daily apparel.*

This style of planning blended a deep understanding of how to assist people with significant disabilities in very practical and detailed ways with the task of forming an appreciation of the unique identity of each person. It gave people who knew and loved a person with profound disabilities a privileged voice in formulating their sense of the person's individuality and worth as a community member and in defining what mattered in a person's life. It gave people with specialist knowledge and skills the chance to define how these things that mattered could be supported and to specify the exact conditions of service under which professionals could most effectively practice. Accordingly, 24-hour plans were more technically specific and detailed across people's days, evenings and weekends, and nights than the other three approaches and they appealed especially to people with specialist training. They became one instrument in gathering a community of practice of nurses and occupational, physical, and speech therapists committed to creating powerful supports for community living for people with very complex bodily needs.

Getting to know you was designed as a way to define the capacities a service system requires in order to provide individualized supports. It enlisted people with disabilities and their families as collaborators in system evaluation and service development rather than as the consumers of a planning process and available services. Plans are precise about the assistance that people need, but far less detailed about how support must be delivered than those constructed in 24-hour planning. Many of the 92 people and families who chose to test their county service system by clearly specifying their individual needs and the costs of meeting them reported some benefit for themselves in making the plans, but what they created also influenced the evolution of their county and state's developmental disabilities services system.

Individual Service Design guided service workers to a deeper understanding of a person's experience and thus to increased empathy and personal identification with the person they assist. It gathered people to reflect on a person's identity by carefully reviewing personal history, thoughtfully drawing out connections between the individual's experience and the processes of social devaluation that shaped institutional living and comparing and contrasting life experiences between the focus person and other members of the group. By imaginatively pursuing a search for socially valued analogues –defined by asking "How does this ordinarily happen for valued citizens?"– the group constructed a test for its own practice. For example, if the focus person lived in a group home the question "What is 'home' like for the rest of us here?" would be followed by the question "In what ways is our group home like and different from what the rest of us consider 'home'?" and "What changes would offer this person more of the benefits of home?"

Personal Futures Planning intersected several communities of practice as Beth Mount's work took her from helping people move into employment from a work activity center in a rural South Georgia county, to assisting people to move from institutions into community living settings in Northeast Georgia, to doctoral research with young African-American adults and their families who were completing special education in places that had very limited service funding, to work with people identified as having the most severe behavioral problems in Connecticut's institutions. At each step, new issues and problems tested, refined, and extended the approach as new colleagues brought new skills and knowledge. Beth's involvement with Citizen Advocacy, a program that makes and supports one-to-one relationships between people with disabilities and other citizens, and with Circles of Support, a way of organizing a person's allies around shared concerns, focused Personal Futures Planning on organizing and extending a person's social supports (Mount, 1988).

Two approaches with distinct roots

Two streams of person-centered planning developed apart from the community of practice concerned about normalization teaching. *New Hats* grew from Emilee Curtis' recognition that many of the dreams and potentials of the people with developmental disabilities she worked with in an activity center were easily overlooked. Indeed, she concluded that service workers too often tried to extinguish people's dreams. Encouraging people to communicate their dreams has led her to develop a variety of powerful aids to thinking, deciding, and communicating. Links to other approaches with person-centered planning emerged later as she made connections to their practitioners and incorporated some of their ideas into her unique formats.

MAPS developed when concern for including children in a residence for children with profound disabilities in a neighborhood school led Marsha Forest to learn about 24-hour planning. A growing community of practice driven by the

desire of Ontario parents to open neighborhood schools and their classrooms to students with disabilities re-shaped the 24-hour planning format. The questions of how a school might welcome and support a student with disabilities whose needs for adaptation challenged typical classroom practice and how a student whose place in school was threatened might get the support to belong and to learn provided the context for MAPS development (O'Brien and Forest, 1989). Two Ontario Separate (Roman Catholic) School Boards, in Hamilton-Wentworth and Kitchener-Waterloo, committed themselves to full inclusion and their schools became sites for visits by educators and family members from around the world. Visitors went away having learned about what it takes for all children to be welcomed as active learners, including the usefulness of MAPS. Efforts to promote inclusion in schools across Canada convened a ten year series of summer institutes at NIMR and McGill University that gathered parents, people with disabilities, teachers, and administrators and, among many other things, taught them how to use MAPS as a foundation for inclusion (Forest & Lusthaus, 1989). Collaboration with Judith Snow, who lives with the support of a circle and has a deep and powerful interest in assisting people to guide their lives by listening to their dreams (Snow, 1992), extended the MAPS process and built strong bridges between MAPS, the creation of circles of support, and Personal Futures Planning.

Different theories and tools

Different interests in planning theories and tools among their originators also differentiated approaches. Individual Service Design stayed very close to its roots in PASS training. *Getting to know you* blended the normalization teaching perspective on gathering information and understanding people's needs with an approach to human service needs assessment and case management that constructed General Service Plans specifying services that would respond holistically to an individual's needs.

Balancing participation in order to assure that professional voices did not drown out the contributions of those who knew and loved a person deeply concerned the originators of 24-hour Planning. They adopted nominal group process techniques (Delbecq, Van de Ven, and Gustafson, 1975) as a way to assure equality of involvement and a balance of influence on the group's results.

Personal Futures Planning incorporated the most extensive exploration of ideas about planning of any early approach to person-centered planning. Some of these ideas came from Beth Mount's doctoral study in public administration, which brought her into contact with research on people-centered development efforts in Asia (Korten, 1981) and with the processes of life/work planning created to assist former clergy and displaced engineers to discover new career paths (Crystal and Bolles, 1974). Some came from her shared reading and discussion with a sub-group of the normalization training community of practice interested in applying the insights of feminist thinkers in disability practice (for one key example, see French, 1985). Some came from her engagement with a community of practice concerned with service planning that intersected the normalization teaching community of practice.

Incorporating lessons from systems planners

A much smaller community of practice involving people concerned about designing community service systems overlapped the normalization teaching network. Under the leadership of Allan Roeher, The Canadian Association on Mental Retardation's National Institute on Mental Retardation (NIMR) became the hub for this network, which gathered associates from across North America and sent them to work with advocates and bureaucrats across Canada. Based in part on his work at NIMR, Wolf Wolfensberger created and repeatedly presented a six day course on planning community service systems through the Training Institute he founded after his move to Syracuse University in 1973.

Experience led to disappointment with the kind of rational planning that assumed it was possible to systematically implement a fully designed system from the top down. It proved nearly impossible to gather sufficient political power to pull off a complete solution. Worse for some members of this network, viewing the approximations of a comprehensive solution that did get implemented from the point of view of the people and families they served, demonstrated that the prevailing idea of "system" was mechanistic and inflexible.

This disappointment pushed Alan Roeher and John O'Brien to look for different ways to understand planning and systems, a concern that led them to collaboration with David Morley at York University's Faculty of Environmental Studies. The Faculty was powerfully influenced by its engagement with Eric Trist, a seminal thinker in understanding and designing adaptive social systems. Through this collaboration, the process of the search conference and the social systems theory behind it became available in the normalization teaching network. (For a current overview of this process and theory, see Emery, 1999 and Trist, Emery, and Murray, 1997.) Involvement with other faculty members brought contact with complementary systems theories and planning practice developed by Russell Ackoff and his colleagues (1974) under the heading of interactive planning.

These links provided four key ideas. First, rapid and connected change means that people and their organizations live in a turbulent environment. In such an environment, it is possible for people to find ways to steer but it is not possible for them to sustain walls strong enough to keep change far enough away to permit successful control from the top. Self-organization leads to success. Second, the best way to understand human situations is to look at them whole, in terms of their interactions and purposes, rather than breaking them down into ever smaller pieces. Third, there are important benefits to gathering people with diverse and conflicting interests to discuss the trends and forces shaping their shared environment, to assess the consequences of not changing, and to create vivid images that communicate shared possibilities for desirable change. Fourth, a shared vision of a desirable future provides a far more robust mechanism for coordinating action in a rapidly changing world than any bureaucratic blueprint for command and control.

Once people in the normalization teaching network began to gather people for search conferences around topics like family support and employment opportunities and attendant care, all that was necessary was for someone to notice that the search conference process could be adapted for a group of people who gathered to focus on one person's future. This is the step that Beth Mount and her collaborators made into Personal Futures Planning.

Continuing development

By 1992 four approaches had become at least eleven.

One additional approach, Personal Histories, drew directly from the normalization teaching community of practice to encourage those who acted as planning assistants to invest time and imagination in helping people with developmental disabilities to construct and communicate an account of their life story (Landis and Pealer, 1990). Initially incorporated into the work of Residential, Inc, a pioneer supported living agency in New Lexington, Ohio, Personal Histories formed a part of the consultation Sandra Landis and Jack Pealer did with agencies in Ohio until about 1990.

The other approaches built on Personal Futures Planning and MAPS as their originators brought different ideas about planning and services to bear on different situations. John Butterworth (1993) and his colleagues in Connecticut developed Whole Life Planning, a way to match planning procedures to the individual preferences of people with developmental disabilities who were seeking employment. Ann and Rud Turnbull created Group Action Planning, adopting ideas from Personal Futures Planning and MAPS to empower families to plan, especially families like their own who are concerned to realize great expectations for family members with behavioral challenges (Turnbull and Turnbull, 1996; Turnbull and Turnbull, 1999). Family First, a project of ARC-Ohio, conducted workshops to support parents in building brighter futures for their young and school aged children, linking family controlled individual planning with organizing for the local and state system changes necessary to align education and human services with visions shared among families. (Holden, 1990). PATH supported individuals and groups in charting strategies for achieving valued futures when sustained and coordinated action is required (Pearpoint, O'Brien, and Forest, 1992).

After exploring Personal Futures Planning, Michael Smull and Susan Burke Harrison (1992) responded to the opportunity to specify what community services would provide for people so profoundly isolated and deprived by their years of institutionalization that they lacked anyone to join a support circle who knew them beyond their reputation for challenging behavior and could not articulate a dream for themselves. Essential Lifestyle Planning aimed to discover and gain service provider agreement to address the simple but important issues for each person which, if ignored, lead to mistrust, unhappiness, and power struggles. A growing community of practice around Essential Lifestyle Planning has generated an array of tools for discovering what matters to people, building a very finely

grained understanding of the rituals and routines that allow people to express their uniqueness, reviewing the quality of plans, incorporating the perspective of skilled service providers, dealing with conflicts, supporting necessary organizational changes, and bridging to other person-centered approaches as a person's dreams grow bigger and stronger and a person's relationships with potential allies grow wider and deeper.

Person-centered planning has grown because passionate concern to support people with developmental disabilities to discover and contribute their gifts brought people together to form communities of practice. These communities of practice supported the creation of skills and knowledge necessary to organize growing numbers of people and agencies around people's vision of a good life in community.

References

Ackoff, R. (1974) *Redesigning the future: A systems approach to societal problems.* New York: John Wiley.

Bellamy, G.T., Horner, R, and Inman, D. (1979) *Vocational habilitation of severely retarded adults: A direct service technology.* Baltimore, MD: University Park Press

Biklen, D. and Bogdan, R. *Handicapism: A slide presentation.* Syracuse, NY: The Center on Human Policy.

Biklen, D. (1977). The politics of institutions. In B. Blatt, D. Biklen, and R. Bogdan, eds. *An alternative textbook in special education.* Denver: Love Publishing Company. Pp. 29-84.

Blatt, B. (1973). *Souls in extremis: An anthology of victims and victimizers.* Boston: Allyn & Bacon.

Blatt, B. (1981). How to destroy lives by telling stories. *Journal of Psychiatric Treatment and Evaluation, 3,* 183-191.

Bogdan, R, and Taylor, S. (1975). *Introduction to qualitative research methods: A phenomenological approach to the social sciences.* New York: Wiley.

Bogdan, R. and Taylor, S. (1976). The judged, not the judges: An insider's view of mental retardation. *American Psychologist 31*(1), 47-52.

Bogdan, R., Taylor, S., de Grandpre, B., and Haynes, S. (1974). Let them eat programs: Attendant's perspectives and programming on wards in state schools. *Journal of Health and Social Behavior, 15(2),* 141-151.

Brost, M., Hallgren-Ferris, B. (1981). *Getting there: Developing individualized service options.* Madison, WI: Bureau of Developmental Disabilities.

Brost, M. and Johnson, T. (1982). *Getting to know you: One approach to service assessment and planning for individuals with disabilities.* Madison, WI: Wisconsin Coalition for Advocacy.

Brown, L., Nietupsky, K, and Hamre-Nietupski, S. (1976). The criterion of ultimate functioning. In M. Thomas (Ed.) *Hey, don't forget about me! Education's investment in the severely, profoundly, and multiply handicapped.* Reston, VA: CEC.

Butterworth, J. (1993) *Whole Life Planning: A guide for organizers and facilitators.* Cambridge, MA: Institute for Community Integration.

Crystal, J. and Bolles, R. (1974). *Where do I go from here with my life?* Berkeley, CA: Ten Speed Press.

DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation, 60,* pp. 435-446.

Delbecq, A., Van de Ven, A., and Gustafson, D. (1975). *Group techniques for program planning: A guide to nominal group and Delphi processes.* Glenview, IL: Scott-Foresman.

Emery, M. (1999). *Searching: The theory and practice of making cultural change.* Philadelphia: John Benjamins Publishing.

Flynn, R. (1999). A comprehensive review of research conducted with the program evaluation instruments PASS and PASSING. In R. Flynn and R. Lemay, eds. *A quarter century of normalization and social role valorization: Evolution and impact.* Ottawa: University of Ottawa Press. Pp. 317-349.

Forest, M. & Lusthaus, E. (1989). Promoting educational equality for all students: Circles and MAPS. In S. Stainback, W. Stainback, and M. Forest. *Educating all students in the mainstream of regular education.* Baltimore, MD: Paul Brookes Publishing. Pp. 43-57.

French, M. (1985) *Beyond power: Women, men, and morals.* New York: Simon and Schuster.

Galloway, C. (1978). *Conversion to a policy of community presence and participation.* Presentation to The 1978 Regional Institutes in Law and Mental Health, USC Schools of Medicine and Public Administration, Los Angeles, CA.

Galloway, C. (1981). *Passage to community participation: A plan for Sharron T. and those who follow.* Sacramento, CA: Author.

Gilbert, T. *Human competence: Engineering worthy performance.* New York: McGraw Hill, 1978.

Gold, M. (1972). Stimulus factors in skill training of retarded adolescents on a complex assembly task: Acquisition, transfer, and retention. *American Journal of Mental Deficiency, 76,* 517-526.

Green-McGowan, K. and Kovaks, M. (1984) Twenty-four hour planning for persons with complex needs. *The Canadian Journal on Mental Retardation, 34,* 1, 3-11.

Holden, L. (1990) *Building brighter futures for our children.* Columbus, OH: ARC-Ohio.

Kindred, M., Cohen, J., Penrod, D., & Shafer, T. (1976). *The mentally retarded citizen and the law.* New York: The Free Press.

Korten, D. (1980). Community organization and rural development: A learning process approach. *Public Administration Review, 41,* 6: 480-510.

Landis, S. and Pealer, J. (1990). *Personal Histories.* Chillicothe, OH: Ohio Safeguards.

Lyle O'Brien, C., O'Brien, J., and Mount, B. (1997). Person-centered planning has arrived… or has it? *Mental Retardation 35,* 480-484.

Mount, B. (1984). *Creating futures together: A workbook for people interested in creating desirable futures for people with handicaps.* Atlanta: Georgia Advocacy Office.

Mount, B. (1988). *What are we learning about circles of support?* Manchester, CT: Communitas.

Mount, B. (1992) *Person-centered planning: A sourcebook of values, ideas, and methods to encourage person-centered development (1992 edition).* New York: Graphic Futures.

Nirje, B. (1969). The normalization principle and its human management implications. In R. Kugel and W. Wolfensberger, eds. *Changing patterns in residential services for the mentally retarded.* Washington, DC: President's Committee on Mental Retardation.

O'Brien, J. (1981). *Normalization training through PASS: Team leader manual (version 1.0).* Decatur, GA: Responsive Systems Associates.

O'Brien, J. (1987). A guide to lifestyle planning. In B. Wilcox and T. Bellamy, eds. *A comprehensive guide to the activities catalog.* Baltimore: Paul Brookes Publishing.

O'Brien, J. and Lyle O'Brien, C., eds. (1998). *A little book about Person Centered Planning.* Toronto: Inclusion Press.

O'Brien, J. and Forest, M. (1988). *Action for inclusion.* Toronto: Inclusion Press.

O'Brien, J., Poole, C. and Galloway, C. (1981). *Accomplishments in Residential Services: Improving the Effectiveness of Residential Service Workers in Washington's Developmental Services System.* Lithonia, GA: Responsive Systems Associates.

Pearpoint, J., O'Brien, J., and Forest, M. (1992). *PATH.* Toronto: Inclusion Press.

Sanderson, H., Kennedy, J., and Ritchie, P. (1997). *People, plans, and possibilities: Exploring person-centered planning.* Edinburgh: SHS, Ltd.

Sibbet, D. (1977). *"I see what you mean!" A guide to group graphics.* San Francisco: Author.

Smull, M. and Burke Harrison, S. (1992). *Supporting people with severe reputations in the community.* Arlington, VA: NASMRPD.

Snow, J. (1992). *What's really worth doing and how to do it: A book for people who love someone labeled disabled (Possibly yourself).* Toronto: Inclusion Press.

Taylor, S. and Bogdan, R. (1977) A phenomenological approach to mental retardation. In B. Blatt, D. Biklen, and R. Bogdan, eds. *An alternative textbook in special education.* Denver: Love Publishing Company. Pp. 193-203.

Thomas, S. (1999) Historical background and evolution of normalization-related and social role valorization related training. In R. Flynn and R. Lemay, eds. *A quarter century of normalization and social role valorization: Evolution and impact.* Ottawa: University of Ottawa Press. Pp. 353-374.

Turnbull, A. P. and Turnbull, H. R. (1996). Group Action Planning as a strategy for providing comprehensive family support. In L. Koegel and G. Dunlap (Eds.), *Positive behavioral support: Including people with difficult behavior in the community.* Baltimore: Paul H. Brookes. Pp. 99-114.

Turnbull, A. P. and Turnbull, H. R. (1999). Comprehensive lifestyle support for adults with challenging behavior: From rhetoric to reality. *Education and Training in Mental Retardation and Developmental Disabilities 34*(4), 373-394.

Trist, E. Emery, F. and Murray, H., Eds. (1997). *The social engagement of social science: A Tavistock anthology. Volume III: The socio-ecological perspective.* Philadephia, PA: The University of Pennsylvania Press.

Weatherly, R. (1979). *Reforming special education: Policy implementation from state level to street level.* Cambridge, MA: MIT Press.

Wenger, E. (1998). *Communities of practice: Learning, meaning, and identity.* Cambridge, UK" Cambridge University Press.

Wenger, E. and Snyder, W. (January-February 2000). Communities of practice: The organizational frontier. *Harvard Business Review,* 139-145.

Wolfensberger, W. (1969). The origin and nature of our institutional models. In R. Kugel and W. Wolfensberger, eds. *Changing patterns in residential services for the mentally retarded.* Washington, DC: President's Committee on Mental Retardation. Pp. 51-179.

Wolfensberger, W. (1972). *The principle of normalization in human services.* Downsview, ON: National Institute on Mental Retardation.

Wolfensberger, W. and Glenn, L. (1972 and 1975). *Program Analysis of Service Systems (PASS), 2nd and 3d editions.* Downsview, ON: National Institute on Mental Retardation.

Wolfensberger, W. (1983). *Guidelines for evaluators during a PASS, PASSING, or similar assessment of service quality.* Downsview, ON: National Institute on Mental Retardation.

Yates, J. (1980) *Program design sessions: OOP (optional operating procedure).* Author.